

**2005 yWhite House Conference on Aging Listening Session
Briefing Paper for Session, Wednesday, December 8, 2004
Environmental Topic Area**

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Home Care and Institutional Care

Our nation has been conducting investigations, passing new laws and issuing new regulations relative to nursing homes at a rapid rate during the past few years. All of this activity will be of little avail unless our communities are organized in such a manner that new laws and new regulations are utilized to deal with the individual complaints of older persons who are living in nursing homes. The individual in the nursing home is powerless. If the laws and regulations are not being applied to her or to him, they might just as well not have been passed or issued.

--The "father" of the Long-Term Care
Ombudsman Program, Arthur S.
Flemming, former Commissioner on
Aging, 1975

We would urge the 2005 White House Conference on Aging to issue specific recommendations concerning the protection of the most frail and elderly, especially to those who live in long term care facilities, beginning with recommendations for the long term care ombudsman program. The communities, of which Dr. Flemming spoke, have not been organized to prevent neglect and abuse or to assure a quality of life for persons living in facilities, those of the "greatest generation," who have contributed so much to our nation.

This is primarily because the Long Term Care Ombudsman Program nationwide has serious problems, beginning with the fact that most states have not assured the independence of the program for it to operate without conflict or interference from the politically powerful.

Generally, citizens advocacy groups believe that the program is ineffective; senior citizens do not know about the ombudsman program. Seniors know more about Sponge Bob Square Pants than they know about the ombudsman program—and that's not much.

Illinois is now on a mission through recent legislation to develop alternatives to nursing homes and we applaud the efforts to develop community services. In this continuum of long term care, from in-home care to facility care, protection is paramount.

In 2003, Illinois passed a law mandating the Illinois Long Term Care Council which has two responsibilities 1) to provide recommendations to the Department on Aging regarding the Illinois Long Term Care Ombudsman Program, and 2) to provide recommendations to the Department regarding the continuum of long term care. Illinois has made significant improvements in its efforts to ensure that the ombudsman program is independent, but this is still “a work in progress.”

Given that a few states have made significant progress in protecting people in long-term care, still the major protection state policies do not exist that would prevent interference with the ombudsman program serving as the voice of residents at the local, state or national level. The Administration on Aging has refused to carry out this mandate, even though there have been two significant national studies on this topic, Institute of Medicine, *Real People, Real Problems; An Evaluation of the Long Term Care Ombudsman programs of the Older Americans Act, 1995* and Helen Bader Foundation, *Independence; the Long –Term Care Ombudsman Program’s Ability to Fully Represent Residents, 2002* and one state study, ICARE Long Term Care Ombudsman Program, et al., *Real People, Real Problems, Real Solutions: Recommendations for the Illinois Long Term Care Ombudsman Program, 2000.*

Therefore, this nation has not seen a model of interdependency of all parties to protect residents in a significant way: ombudsmen, families, advocacy groups, facility owners, surveyors, policy makers, and community leaders, except in a few isolated cases. This inability of the ombudsmen to speak out on what is needed has prevented an understanding that there needs to be a hierarchy of fundamentals in operation in order to bring communities together. Rarely is there an enlightened community that is able to change poor long-term care systems, if the proper foundation has not been laid.

Most of our nation’s protection efforts for the elderly in long term care facilities have been like shifting sand. We need to build a rock-solid foundation of protection, beginning with assuring the independence of the ombudsman program.

This paper addresses four critical fundamentals of protection, beginning with independence and resources for the ombudsman program that, in turn, will result in effective and independent family councils, changes in the facility survey process and facility culture change. The following can be thought of as the “hierarchy of protection” needs:

- To implement the present laws and regulations to ensure that there are no organizational or political conflicts,**
- To empower independent ombudsmen programs,**
- To train a sufficient number of communities volunteer ombudsmen,**
- To sustain and educate family councils and citizen advocacy groups,**
- To awaken the policy makers and the community leaders to the issues of neglect and abuse,**
- To change the survey and penalty system,**
- To cut off the money when there is abuse or neglect,**
- To promote the culture change in every aspect of long term care,**

Only then will we be able

To actually protect long term care residents' rights to quality care and a quality of life

Recommendation: Strengthen and Ensure the Independence of the Ombudsman Program

Rising costs in health care and lack of trained staff in nursing homes have caused the federal government to fund multimillion-dollar "quality care" projects to ensure that seniors with disabilities who live in these homes are not subject to abuse and neglect. There have been some improvements in nursing home practices, such as use of fewer physical restraints, but not improvement overall. Most facilities do not provide quality care or a quality of life, both of which are required by federal law.

Essentially, all of the federal and state initiatives to improve care have met with limited and temporary results; the federal government has yet to use state and local resources to the fullest extent to address ongoing abuse and neglect that occurs in facilities. Long-term care ombudsmen are mandated to work with legislators, communities and citizens groups to correct these problems through public awareness, but are too conflicted to do so. This program is unable to protect the well being of residents in long-term care facilities.

The ombudsman program has not been supported by the Administration on Aging to enable the program to enlist state legislators to support stricter enforcement of existing requirements or to gain support of people in local communities to strongly and openly advocate for the protection of residents' rights.

Perhaps the most important duty of the ombudsman program is to identify and analyze residents' complaints to determine the underlying problems and use that information to eliminate neglect and abuse, or to publicly demand that the state take action to close the facility.

The Older Americans Act requires that the Long Term Care Ombudsman Program be free of conflicts of interest and free from willful organizational and other interference in the performance of its duties in order to wholly represent residents before state legislatures and the public, including suing a facility, if necessary.

Research has shown that to be effective, an ombudsman program must be able to pursue independently all reasonable courses of action that are in the best interest of residents, including, but not limited to, legislative advocacy, testifying on issues the program deems important, contacting the media, meeting with government officials, supporting the formation and sustaining of family councils, working with citizens groups and carrying out all other responsibilities set forth in the Older Americans Act.

The Administration on Aging is responsible for approving the state plans for the aging programs and monitoring assurances that the Long Term Care Ombudsman Program is in compliance with the Older Americans Act.

Because of the inability of the Long Term Care Ombudsman Program to act without interference, long-term care facility residents and their families are harmed. The ombudsman program, nationally or by states, cannot do its work without interference. The inability of the ombudsmen to speak the truth denies residents their rights each and every day, including the basic rights to drink water and be adequately fed in hundreds of facilities.

The Administration on Aging has interfered with or ignored state advocacy groups in attempting to ensure that their ombudsman programs are able to act without conflict by the following:

**Approving state plans when there was information that the state did not have policies or procedures to prevent organizational conflict,
Approving state plans when there were data and information that indicated that the ombudsman program did not comply with the Older Americans Act,
Not monitoring the program,
Not answering legitimate questions about Administration on Aging policies concerning the ombudsman program,
Not assuring that each state ombudsman program has an independent legal counsel,
Not assuring that each state has an adequate awareness plan, and
Not promulgating regulations based upon the 1992 and 2000 amendments to the Older Americans Act.**

Specific Recommendation:

The Administration on Aging should immediately:

Develop and implement procedures to ensure that states are held accountable for assuring the ability of ombudsmen to pursue independently all responsible courses of action that are in the best interest of residents, including eliminating conflicts of interest and willful interference with representatives of the program, and to establish effective mechanisms to receive and resolve citizens' complaints about interference or conflicts of interest in the ombudsman programs.

Promulgate regulations for the ombudsman program consistent with the language and intent of the Older Americans Act that supports the program's authority and ability to work without interference or conflict of interest; and

Hold states accountable for the provision of adequate resources, including sufficient funding and legal counsel that is without conflict, in accord with the Older Americans Act.

Recommendation: Develop, Maintain and Strengthen Independent Family Councils

Many families, personal representatives, and friends of residents are in nursing homes and other types of long term care facilities many hours each day. These people, when properly trained, should be a vital component in protecting residents' rights, including quality of care and a quality of life.

These residents' families and friends are critical to monitoring the quality care and quality of life provided to residents on a daily basis because there are insufficient numbers of trained ombudsmen and certification surveyors to monitor care of facilities

The present federal laws do not adequately establish the independence of family councils, the facility's responsibility to encourage their formation, or establish adequate protection for residents, their families, personal representatives and friends against retaliation when they raise concerns over care issues.

If the communities are going to be involved in the protection of the most frail and elderly, it will take the families, designated representatives and friends, empowered through family councils, who are trained about the rights of residents by long term care ombudsmen, to make significant changes in facilities and to inform the community about residents' problems.

Specific Recommendation: Congress, the Centers for Medicare & Medicaid Services, Administration on Aging, other federal departments and agencies should incorporate the establishment of independent family councils for all types of long term care facilities into law or regulation.

Facilities should be required to assist in the development of independent family councils by the provision of (1) a specific staff person to provide prompt assistance to the family council upon its request and to respond promptly, acting on behalf of the facility, to written requests or concerns that result from family council discussions, meetings, or activities; (2) adequate private space for meetings; (3) adequate space on a prominent and easily visible bulletin board in a public area of the facility for meeting notices, minutes, newsletters, or other pertinent information from the family council; (4) notice of family council activities, including time, place, and date of meeting; in any regularly-scheduled mailings sent by the facility to family members; and (5) information about the family council to new residents, family members, and personal representatives during the admissions process, including the name, address, and phone number of family council representatives to contact for further information.

The requirements should prohibit facilities from interfering with or retaliating in any way against residents or members of independent family councils because of the development of an independent family council or any protected activities of family councils.

Under current regulations, the Centers for Medicare & Medicaid Services should direct surveyors to determine facilities' compliance with requirements governing family councils in each survey and direct survey agencies to impose stringent remedies for violations of regulations governing family councils without giving facilities a prior opportunity to correct. The states should be given guidance on establishing a complaint process for hearing the grievances of family councils, or from individuals who wish to establish or participate in family councils, when the facility fails to comply.

Recommendation: Correct Problems in Survey Process of Facilities

During the last two years, serious problems in the long term care survey and certification process have been identified by the HHS Office of Inspector General in a report dated March 2003, by the Government Accountability Office, and by Senator Charles E. Grassley, a senior legislator, who has historically strongly focused on protecting the rights and needs of long term care residents.

These serious problems identified, include:

- Existence of strong political or other pressures from sources other than residents;
- Insufficient numbers of trained ombudsmen and surveyors to monitor care;
- Cyclical compliance of facilities resulting from predictable timing of annual visit;
- Deletion of deficiencies or downgrading of scope and severity of deficiencies;
- Lack of thorough investigation of complaints;
- Lack of independence of family councils;
- Lack of adequate protections of residents and their families, personal representatives, friends of residents, and other advocates against retaliation when they raise concerns over care issues;
- Lack of right and opportunity for such residents, designated representatives and families to appeal determinations of "no findings" or initiate an informal dispute process themselves on behalf of residents, or to participate in the existing informal dispute process; and
- Lack of adequate probes to insure the right of residents to quality of care and worth of life.

Specific Recommendation: The Centers for Medicare & Medicaid Services should revise existing regulations or promulgate new regulations, and revise existing guidelines or promulgate new guidelines, to correct the problems identified in the reports of the HHS Office of the Inspector General, the GAO, and Senator Charles E. Grassley, along with such other problems as may be identified in the process.

Recommendation: Require Deep Culture Change in Long Term Care Facilities and Other Long Term Care Settings

OBRA in 1987 established standards and regulations to ensure nursing facility residents the right to “care and services to attain or maintain the highest practicable physical mental and psychosocial well being;” but this has not occurred even with this law. One only has to look at the certification agency’s survey reports, ombudsman program complaints, and research on long term care to know how deeply entrenched is the present dehumanizing institutional system for caring for the most frail and sick in too many facilities.

In recent years, several groups of facility owners, administrators and long term care ombudsmen have promoted deep culture change in different ways, including the Eden Alternative, Regenerative Community, Resident Directed Care, Individualized Care, and the Pioneer Movement. The Illinois Long Term Care Ombudsman Program has spearheaded the culture movement the past few years. This has brought about change in several Illinois facilities and provided training for many facility staff.

But deep culture change has not achieved widespread usage in long term care settings; in fact, some facilities will not even try these methods that bring quality care and a renewed zest for living for residents.

Deep culture change encompasses practices, which nurture the human spirit as well as meeting medical needs, which follow the residents’ routines rather than those imposed by the facility or other caretakers, which encourage appropriate assignments of staff with a team focus to make deep culture change possible, which allow people to make their own decisions. Deep culture change promotes spontaneous activity opportunities, which encourages and allows residents to be treated as individuals.

For most facilities, deep culture change would be an important component of the right of residents to “care and services to attain or maintain the highest practicable physical mental and psychosocial well being.”

Specific Recommendation: Congress, the Centers for Medicare & Medicaid Services, Administration on Aging, other federal departments and agencies be called upon to incorporate deep culture change as an important component of requirements for quality of care and quality of life for individuals in all long term care settings. Appropriate laws, regulations, initiatives and policies should encourage facilities to make and sustain a culture change and should penalize those that will not try these methods that promote quality care and a quality of life for people needing long term care.

I appreciate the opportunity to provide these critical issues regarding the protection of people in the long term care continuum to be considered by the Policy Committee of the 2005 White House Conference on Aging. Dr. Margaret Niederer